

connecting for change

UPDATES FOR THE RARE EPILEPSY COMMUNITY

Hello, nice to meet you!



Karen and her daughter, Samantha

Hello! I'm Karen Utley, and I recently joined Praxis as the **Epilepsy Patient Advocacy Lead**. I am a nurse, and like so many of you, a passionate advocate for those living with rare epilepsies because my daughter, Samantha, has CDKL5 Deficiency Disorder (CDD).

When Samantha was diagnosed at 20 months, I was desperate to help her, and others like her. In 2009, I co-founded the International Foundation for CDKL5 Research, an organization that funds research and provides support for patients and caregivers affected by

CDD.

I quickly became adept in advocacy, community building and discussions with researchers and industry. As a parent on this journey, I know how important it is to connect with people who understand, so please feel free to reach out!

Above all, I am deeply committed to improving the lives and futures of those facing pediatric epilepsies. Praxis has a deep pipeline of programs designed to treat genetic epilepsies. Joining the Praxis team has been fast paced, to say the least, because there is so much to communicate! I very much look forward to our partnership.

-Karen



PRAXIS RESEARCH UPDATES

At Praxis Precision Medicines, we have a passion for developing new medicines for genetic epilepsy patients. We have two potential medicines for early onset SCN2A-Developmental Epileptic Encephalopathy (DEE) in clinical study planning phase.

PRAX-222 is an antisense oligonucleotide (ASO) being developed for early onset/gain-of-function SCN2A-DEE, with the potential to be the first disease-modifying treatment for this condition by treating seizures as well as other symptoms of the disease.

PRAX-562 is a small molecule being developed for rare genetic DEEs with the potential to be a novel anti-seizure medicine that regulates sodium channel dysfunction in a manner different from current standard of care.

COMING SOON

- **Register Now: Praxis SCN2A Live Program Update Webinar on August 30, 2022, 6pm EDT**

Please join us to hear updates from the Praxis Epilepsy Program, including PRAX-222 and PRAX-562 program updates and more.

[Register for the webinar here.](#)

- **SCN8A + SCN2A Phase 2 trial**

Praxis plans to initiate a Phase 2 trial of PRAX-562 in patients with SCN8A and SCN2A DEEs in the second half of 2022. Please register for the webinar **above** to learn more.



COMMUNITY CONNECTIONS

- ***Welcomed* at the Families SCN2A Summer Seminar – July 28-29**

This amazing event, hosted by [Families SCN2A](#), was a powerful experience and an important opportunity to connect with the SCN2A community in person! Praxis was honored to be a platinum sponsor, and the turnout of researchers, scientists and families is a testament to how the community has grown!



- **Attended the World TSC Conference – July 28-31**

Hosted by the [TSC Alliance](#), this was an opportunity to connect with patients, healthcare professionals, caregivers and researchers to learn more about the unmet needs of this community of 1 million people struggling with tuberous sclerosis and the seizures and neuropsychiatric challenges associated with it. Being part of the community allows our researchers to develop meaningful treatments to improve the lives of the families.



Do you have an event that you would like to put on our radar? We would love to know about it, and we will add it to the Community News section of [scn2a.com](#). Please send information to patientadvocacy@praxismedicines.com



TUNE IN

- **Thursday, September 8 at 1 pm ET / 10 am PT** – Join Praxis CEO and President, Marcio Souza, along with Associate Director of Natural History and Diagnostics Lead, and SCN2A parent, Kelley Dalby, for a webinar hosted by *Fierce Biotech*. Kelley will be sharing her personal journey with her son, and discuss how she works at Praxis to accelerate development of potential therapies utilizing new technologies. [Register here to join the discussion.](#)

LET'S STAY IN TOUCH

Have questions or would like to connect? Please feel free to reach out to us at patientadvocacy@praxismedicines.com.

You can also connect with Praxis on [Twitter](#) and [LinkedIn](#).

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